Enable all people living with a rare disease to receive an accurate diagnosis, care, and available therapy within one year of coming to medical attention

**IRDiRC has set three goals for the decade 2017-2027**

- To develop the means to diagnose patients with suspected rare diseases within one year of coming to medical attention.
- To develop 1,000 new therapies for rare diseases, and particularly for diseases with no approved treatment.
- To create methods for assessing the impact of diagnoses and therapies on rare disease patients.

**Members**

Launched in April 2011 at the initiative of the European Commission and the US NIH, IRDiRC unites organizations invested in RD research (currently nearly 60 including governmental and nonprofit funders, industry and umbrella patient advocacy organizations), working collaboratively with scientific researchers to advance RD research worldwide.

**Activities & Resources**

IRDiRC organizes several activities and provides many resources to the RD research community.

**Task Forces**

Created to tackle specific time-limited topics within RD research proposed by the Consortium’s Constituent and Scientific Committees.

Proposes solutions through policy recommendations and/or technical applications including platforms, tools, standards and guidelines.

Members are nominated based on their expertise and include key players of diverse backgrounds.

Meetings through teleconferences and concluded by face to face.

The IRDiRC strategic Roadmap is updated yearly with new prioritized actions.

**Recognized resources**

Quality label highlighting key resources (eg, standards, guidelines, tools, platforms) designated to advance RD research and development.

Open to all resources within IRDiRC’s focus and mission and which have multinational connectivity and audience. Application: Peer-reviewed with rolling submission.

**Funders Constituent Committee (FCC)**

**Companies Constituent Committee (CCC)**

**Patient Advocacy Constituent Committee (PACC)**

**REAMS**

- Rare Diseases Research Ecosystem
- Infrastructure
- Acceleration
- Monitoring
- Support

**BEPERS DISTRIBUTION AROUND THE GLOBE**

**VISION & GOALS**

IRDiRC Scientific Secretariat, Inserm, Paris, France; Sanford Health, Sioux Falls, South Dakota, United States; Fondazione Telethon, Milan, Italy

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